Novy's Guide to FEEDING TUBES

for fun & funky folks

Written by Novy

Fact-checked by Dr. Ro (a real doctor!)

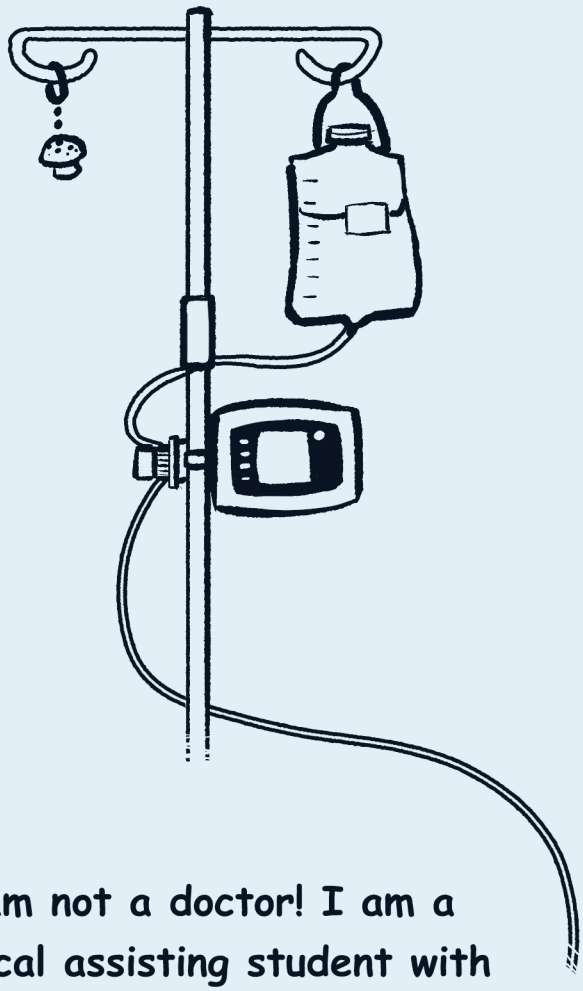
Illustrated by Lore

Some things before we begin:

This guide's usefulness is not limited by age (you can be a teen, or in your 50s! anything works) but it does assume

you, the reader,

are getting a feeding tube yourself.



This is much less aimed at parents with young children or adult children of elders. There are lots of other guides aimed specifically at these groups out there.

I am not a doctor! I am a medical assisting student with a public health background.

This has been

fact-checked by a real doctor,

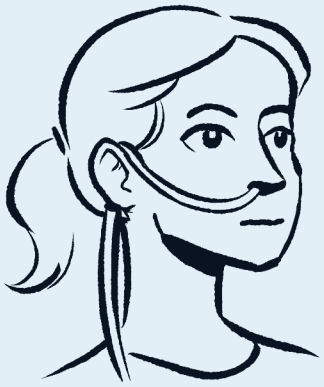
but everyone's situation is different and they need different things.

This is **not medical advice**, it's basic information and life hacks.

If you're **unsure about anything** please ask your doctor, and remember I'm just a person on the internet who doesn't know you or your tubes.

there are several types of feeding tubes, categorized by how it enters your body and where it ends

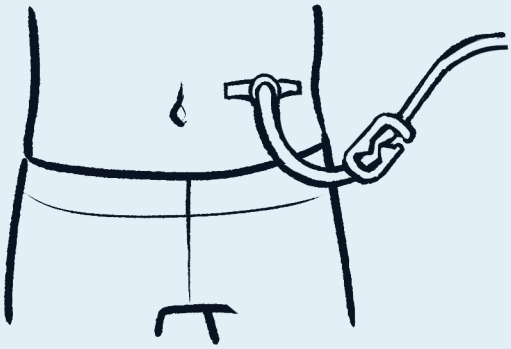
nasal tubes



(nasal tubes are often short-term, used to trial tube feeds before going through surgery)

surgical tubes

(Also known as "percutaneous", meaning they pass through the skin)



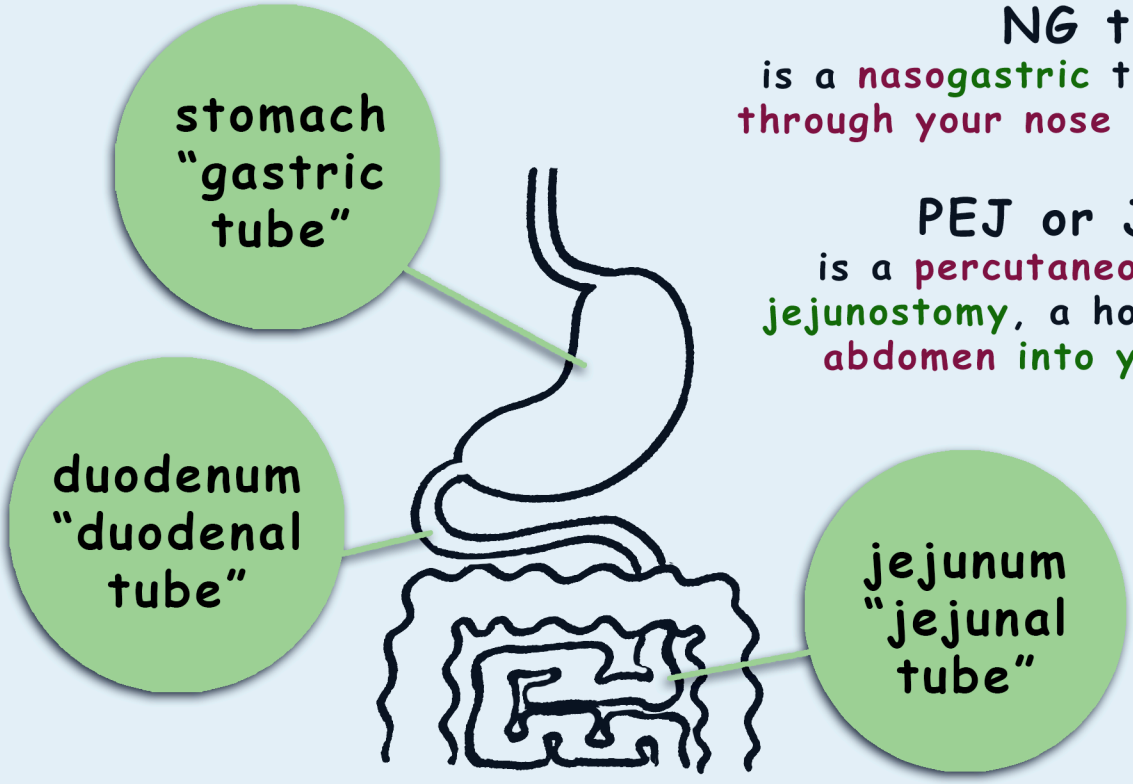
People refer to them with acronyms:

NG tube

is a nasogastric tube, which goes through your nose to your stomach)

PEJ or J-tube

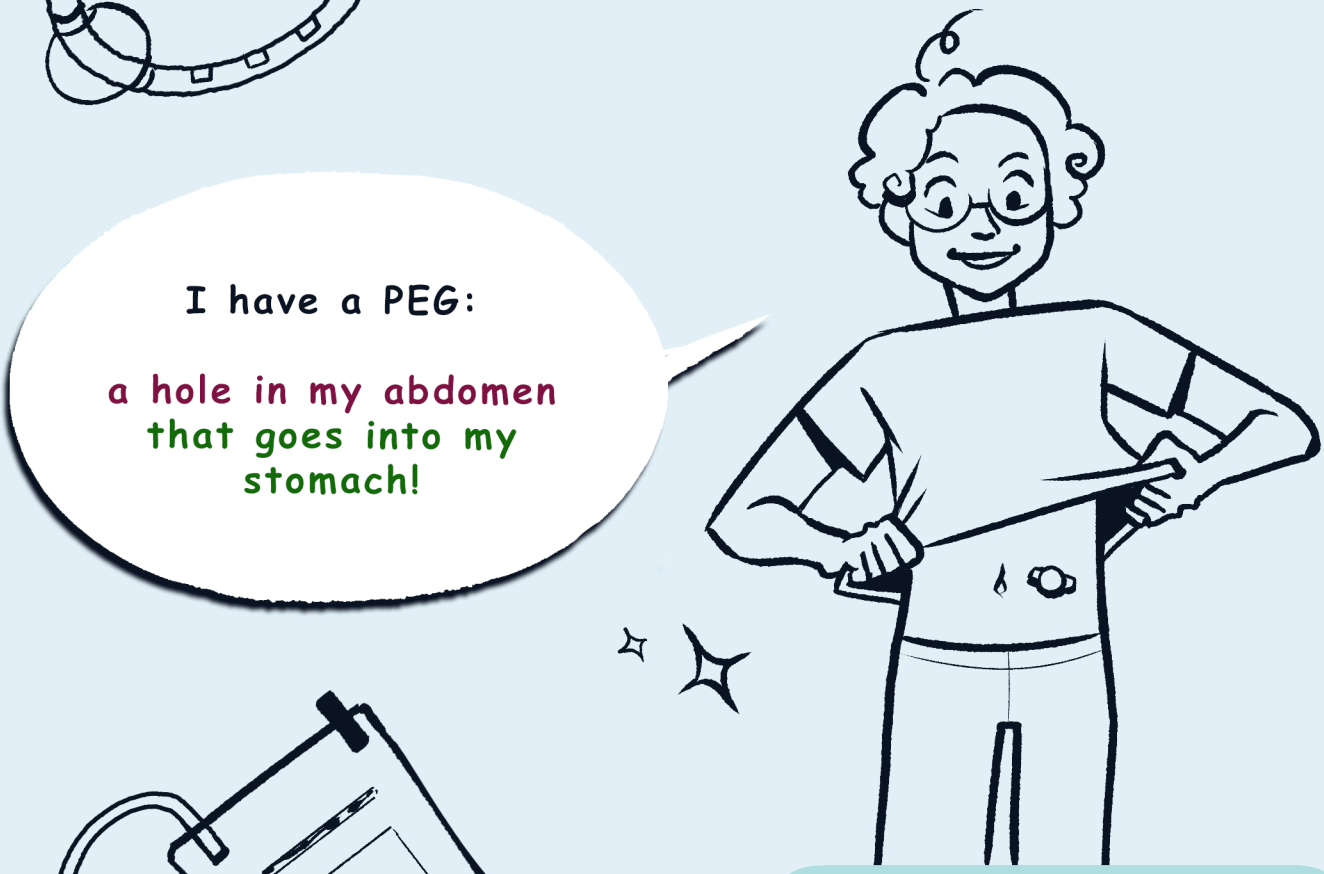
is a percutaneous endoscopic jejunostomy, a hole through your abdomen into your jejunum.

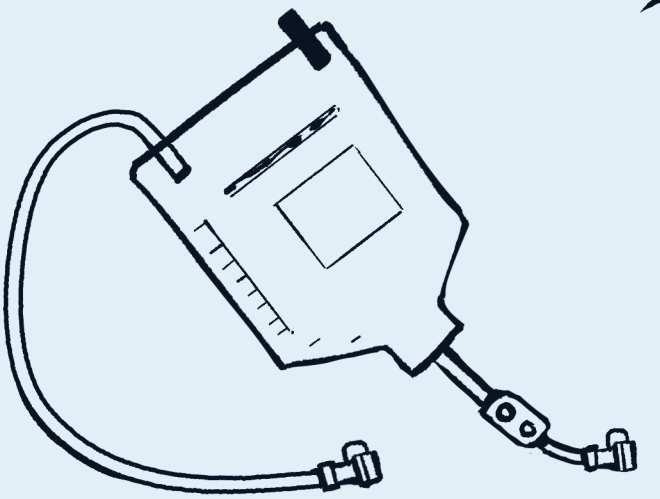


GJ-tubes

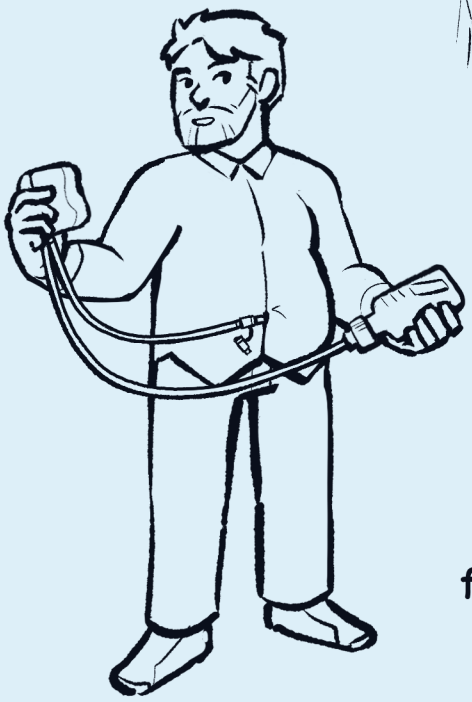
where you have a hole into your stomach but there's a long tube threaded into your jejunum from your stomach.

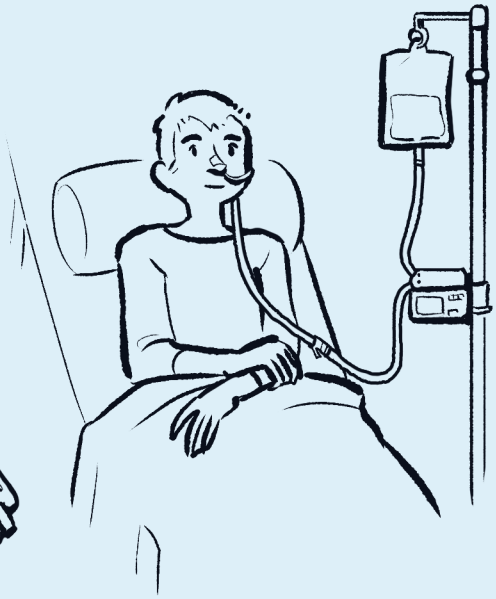
JGs allow you to have access to both your stomach and jejunum through only one surgically created hole.





some gastric tubes aren't used for feeds, but for draining out stomach contents

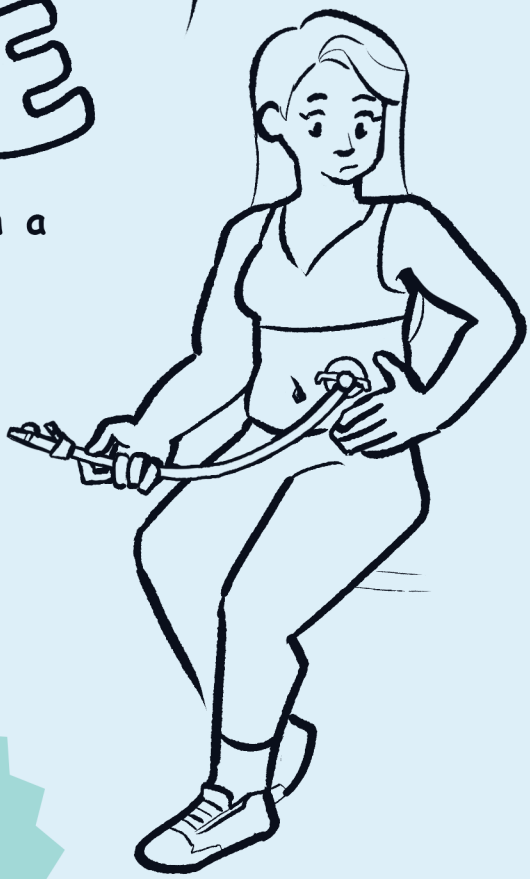




if you know anything about feeding tubes, you've probably heard the word

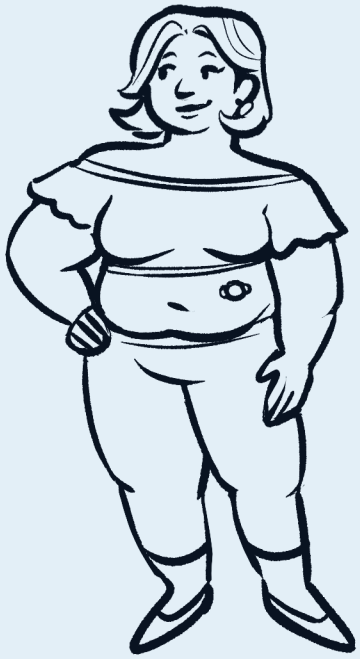
TUBIE

a "tubie" is anyone with a feeding tube!



tube feeding is also called enteral feeding!

there's no "wrong way" to be a tubie!



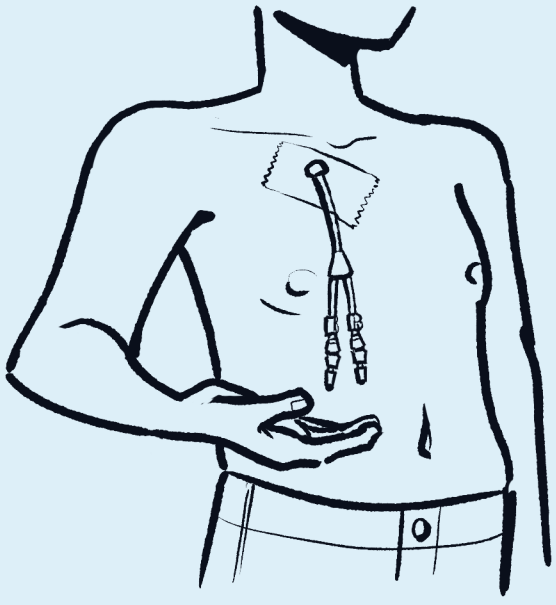
You don't have to be skinny to need a feeding tube: The popular conception is that malnourished people are all very thin. This is not true! Fatphobia is really pervasive, but if you're worried or ashamed to need a tube because you feel like you weigh too much, I promise you don't. There are people with tubes out there who look like you and you have just as much right to nutrition as anyone else.

Stoma: A surgically created hole in the body. The hole a feeding tube goes through is a stoma.

However, there are many different kinds of stomas -- people may have a feeding tube and also an ostomy, which are stomas meant to remove waste like urine or feces.

NPO: non/nil per os, meaning "none by mouth" or you can't eat orally. Can also simply be NBM for "none by mouth."

Some tubies are NPO, but not all! I get about 1/4th of my calories by mouth, and I know some people who drink small sips of tasty drinks and then drain them from their g-tube. It's a conversation to have with your doctor!



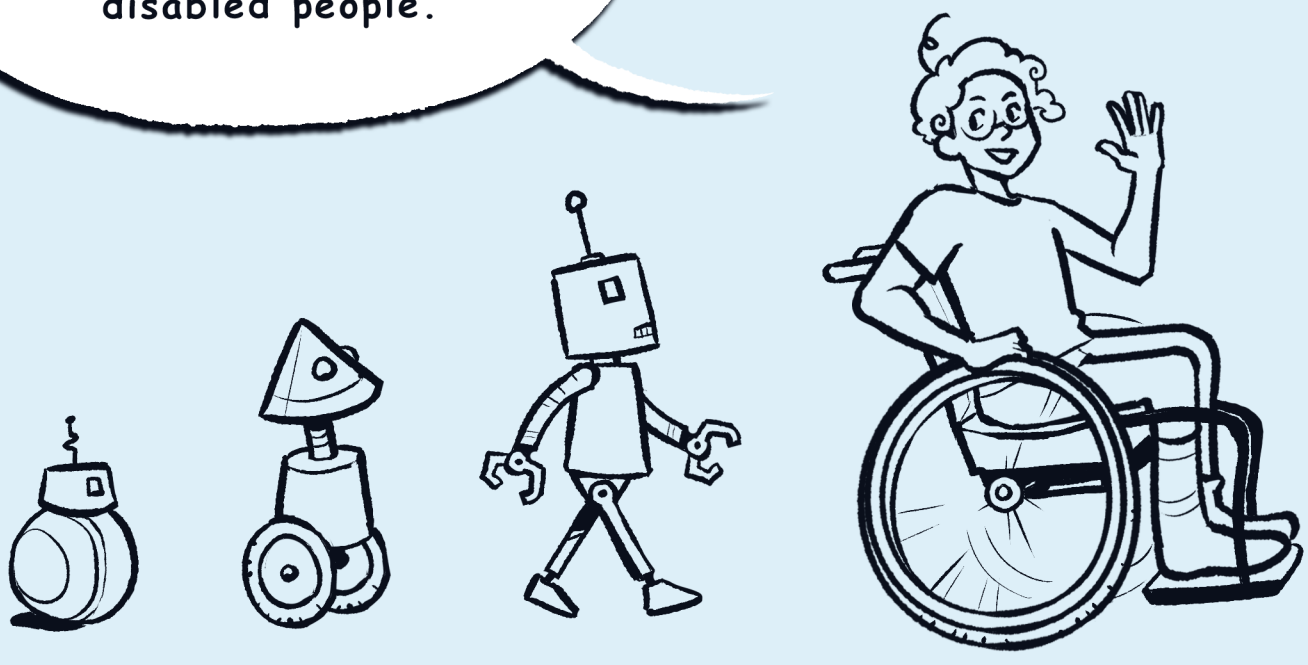
TPN: Total parenteral nutrition, or "being fed through your veins." This is beyond the scope of this zine! However, you'll probably hear about this if you spend time in feeding tube spaces.

I do not really remember my surgery because I had a bad antibiotic reaction and Experienced A Sense Of Impending Doom.

Mostly, I can say -- I know it's scary, and you may have a lot of complicated feelings.

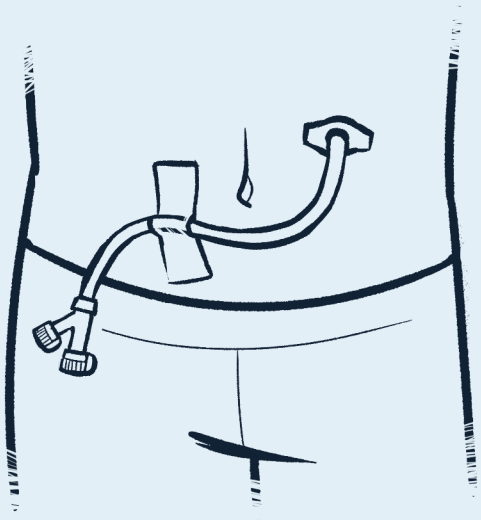
It's okay. Eating is held up as some sort of fundamental human experience, and it's absolutely not, but it's okay to grieve. It's okay to wonder what will change, or worry about how you'll look now.

However, in my personal opinion, you are going to become a cyborg and that's badass. The cyberpunk future is here and it's disabled people.



It will probably hurt after the surgery; I found ice was really helpful. I didn't find it too bad, but other people have said it was extremely painful for them (including my friend kelpforestdwellers, who looked over this guide).

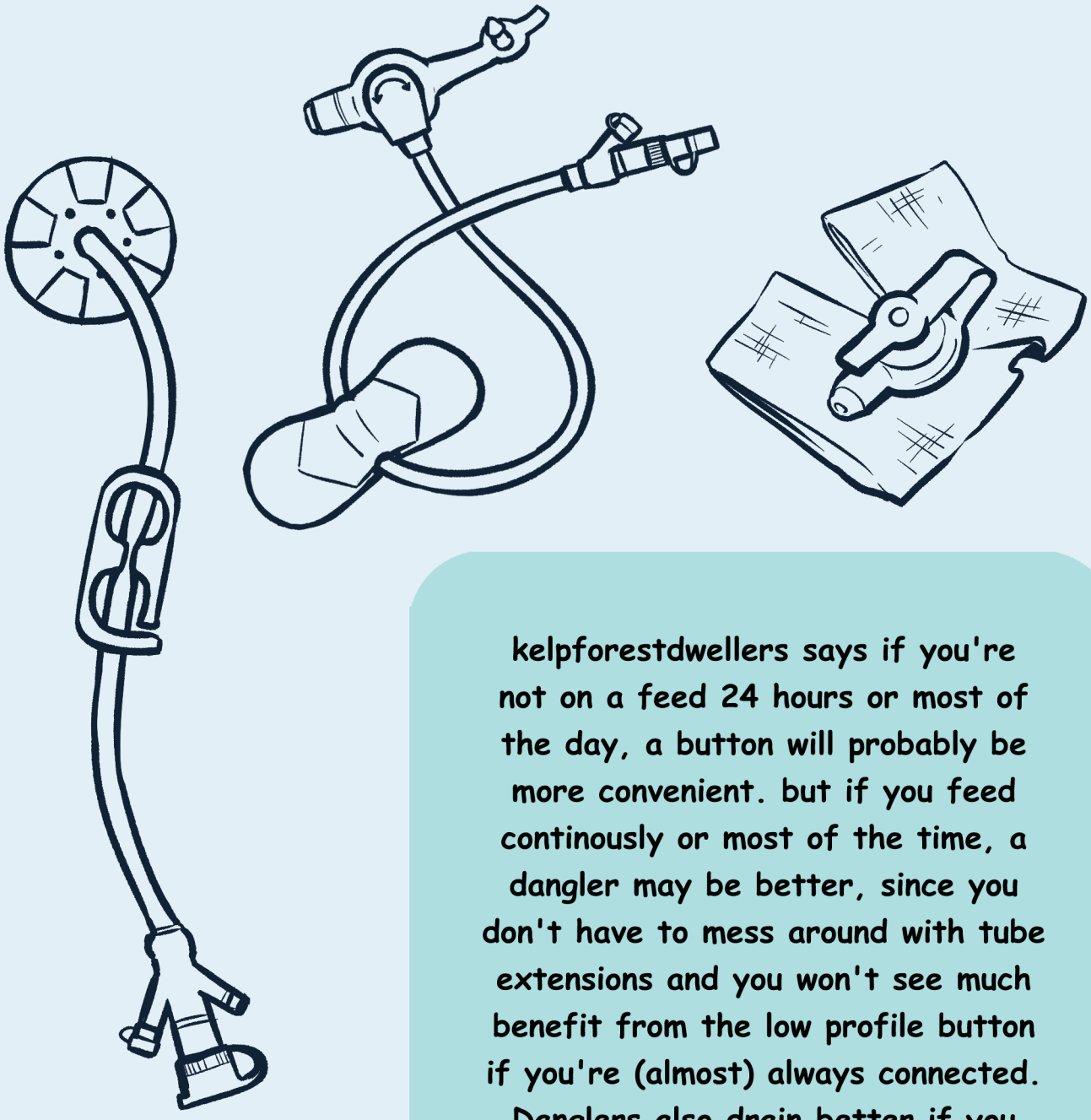
Try to have a pain management strategy in advance. I would sleep with a body pillow and an ice pack tucked between the pillow and my body.



You'll want to tape the dangly end to your stomach, otherwise, it'll get yanked. You'll have adhesive on your stomach all the time, so you want to find a tape that doesn't irritate your skin. I use a soft blue medical tape from the grocery store. Many people really like Grip-Lok.

kelpforestdwellers says off-brand Grip-Lok is their go-to!

After your stoma heals, you might be able to request to replace your dangler tube (long, you need to tape it up) with a button (much smaller, no need for tape.) You need to replace tubes regularly so it's not an extra procedure, it's just a quality of life improvement for a lot of people! However surgical tubes always have a dangler placed first.



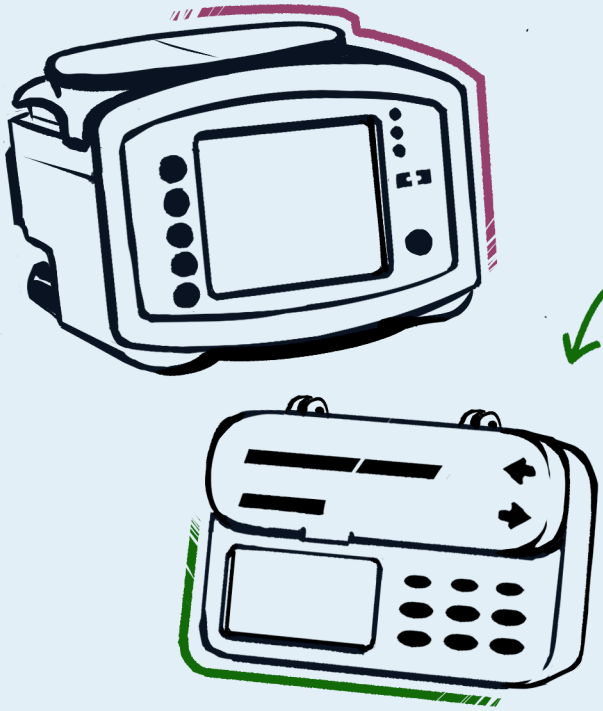
kelpforestdwellers says if you're not on a feed 24 hours or most of the day, a button will probably be more convenient. but if you feed continously or most of the time, a dangler may be better, since you don't have to mess around with tube extensions and you won't see much benefit from the low profile button if you're (almost) always connected. Danglers also drain better if you drain stomach contents.

People use their feeding tubes in different ways.

Some people give **bolus feeds**, where a large volume of formula is drained into the stomach all at once. If your tube enters your duodenum or jejunum, this is not possible; I have a tube that enters my stomach but I also am unable to bolus feed.

In these situations, people can pump small amounts of formula in over a longer period of time! Some people run their pump 24/7, and some people do shorter feeds.

I run mine overnight while I'm sleeping.



There are two main types of pumps: Kangaroo Joey and Moog Enteralite Infinity.

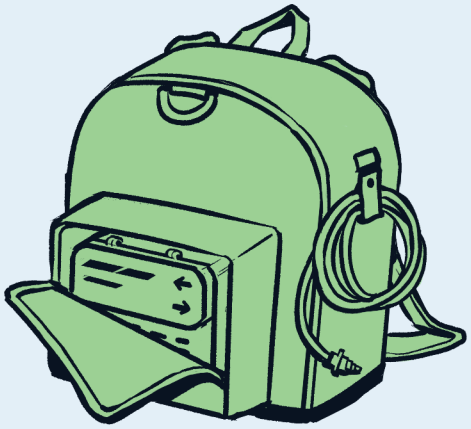
Kangaroo Joey is a lot heavier. If you have the choice and you're planning to do anything besides sleep while hooked up, I'd ask for Moog. If it doesn't work for you you can try the Joey! The infinity pump handles blended food better, but the Joey does flushes of water automatically. It really depends on what you need, like many things.

Accessories

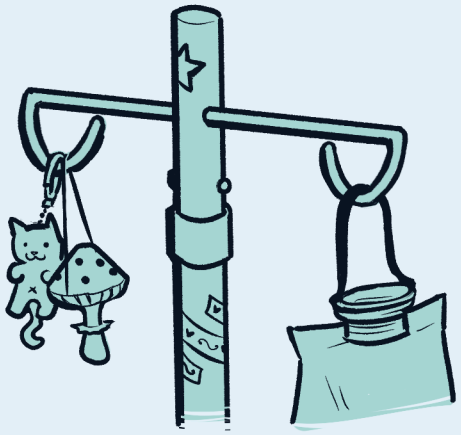
If you are prescribed feeds throughout the day you can get a backpack to carry them through insurance, but they are usually ugly!

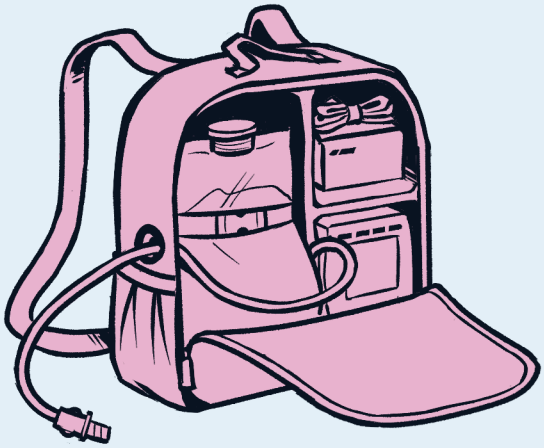
There are backpacks out there to buy (try Etsy) or if you can sew, tutorials for modifying an existing backpack for your tube.

Also, free arms can be used to replace IV poles, but I've never used one. They're really expensive! I've heard good things, though.



If you go with an IV pole you can decorate it and that's always nice! Mine I covered with washi tape and silver star tinsel.





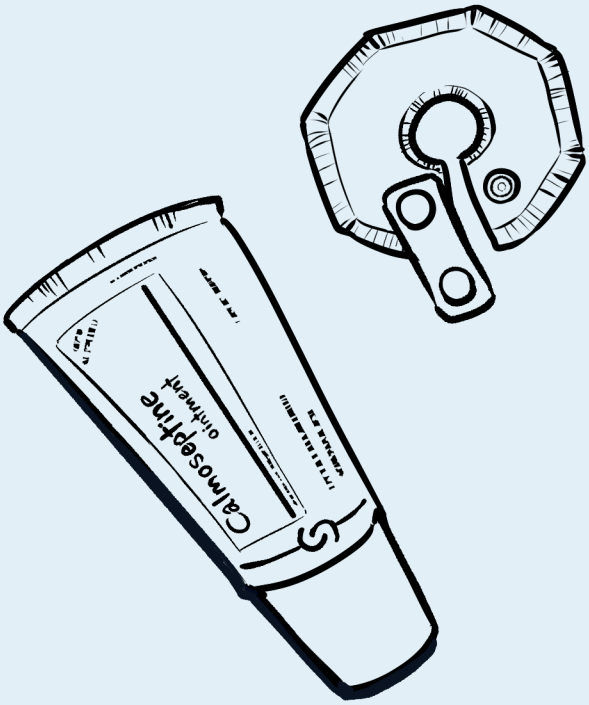
Your extension set may kink up when you're running feeds, and you may be unable to flush it or have formula go through without unbending the kink. If this happens often I like to wrap the whole extension set in a sticky tape; it makes it just a little bit less floppy.

My friend Crow uses zip-ties on their dangler tube to keep the bumper from sliding around, on the advice of their nurse.

the Hole

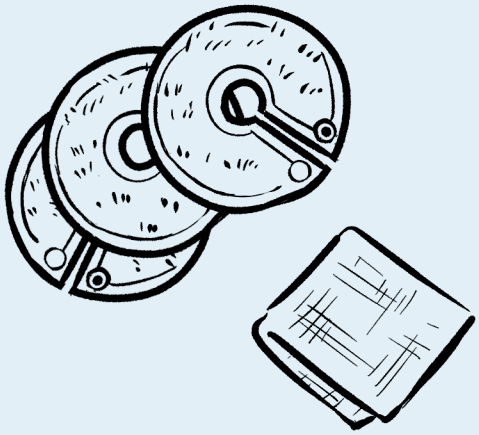
Lots of people get granulation tissue around their stoma. Granulation tissue is a fleshy overgrowth; it can look like red, bumpy, swollen flesh.

This is your body trying to heal around the tube. It can be quite painful; often doctors will use silver nitrate to burn it off. Using gauze, a tubie pad, or lotion can help with that.



kelpforestdwellers' tip: calmoseptine is also very useful for this

I get a lot of what is unscientifically best described as crusty stoma gunk -- it can be a lot of things, from leaking stomach contents to dead skin cells and oils. I clean my stoma regularly using a qtip and warm water because otherwise my skin gets acid burns and irritated.



Tubie pads are really helpful for some people. I like ones with fluffy backs but personal preference varies. There are lots of people who make them, try different types until you find one you like.

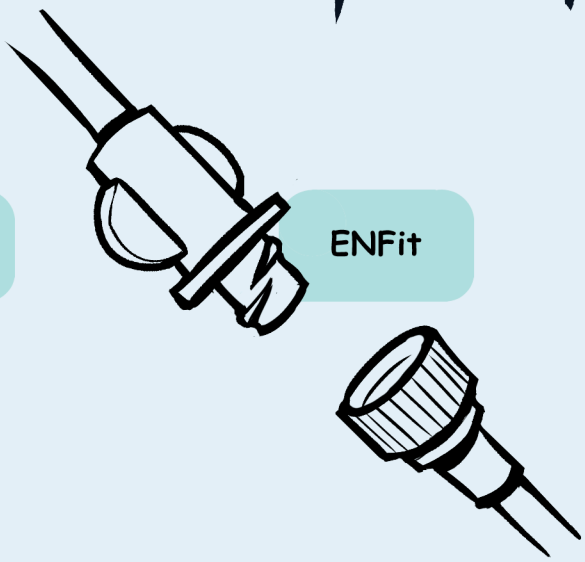
You can also use single-use gauze if reusables are not an option.

Connectors

There are 2 ways to connect your tube-in-you to your feeding pump:

ENFit and classic (or "Christmas tree") connectors.

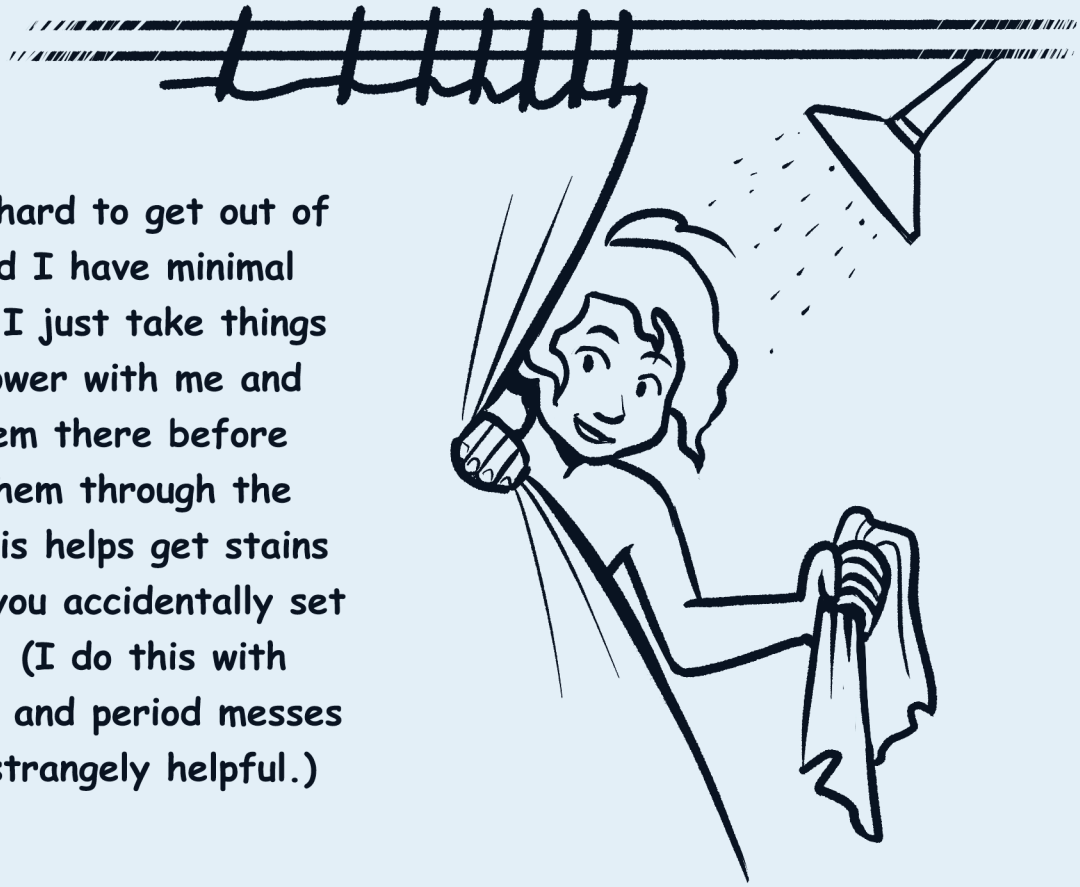
I used classic for a while and did not like it. I'd often come unhooked and not notice. I'd wake up in a pool of formula or look down and see my shirt was covered in stomach contents.



ENFit screws in and it's much nicer for me, because it doesn't pop apart as easily.

Personal preference, but ENFit is my favorite (and it's meant to reduce medical error -- no chance of accidentally screwing your feeding tube meds into your central line, or putting something that should go to your jejunum into your stomach.)

You WILL probably get formula everywhere, sometimes in public and sometimes in the middle of the night. It.. sucks. Keep clean sheets nearby. I didn't find it practical to bring changes of clothes with me when I left the house, but sometimes I have wished I did! Having a shirt and a sweater has been helpful because I can just take off the dirty shirt in public.



Formula is hard to get out of fabric and I have minimal energy, so I just take things in the shower with me and scrub them there before running them through the washer. This helps get stains out before you accidentally set them in. (I do this with incontinence and period messes too. It's strangely helpful.)

Hole Safety

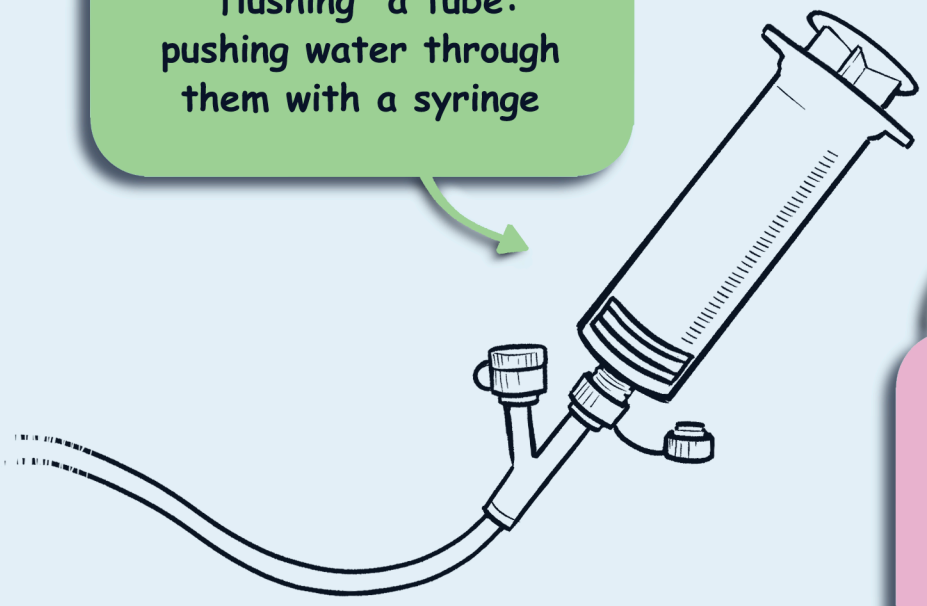
You can get infections around your stoma even after your wound has been healed for a few years. Be sure to ask your gastroenterologist to culture them! Sometimes they'll just give you broad-spectrum antibiotics when you have a yeast infection instead. However, infections can get bad fast in a stoma, so don't wait too long.

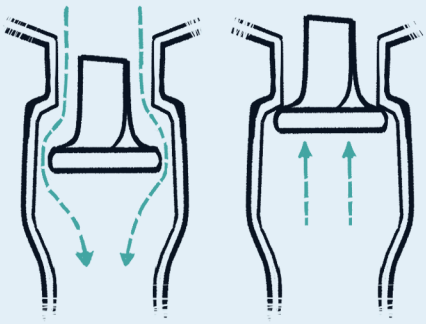
If you're a scientist, like me, you may wonder how to handle your stoma and tube in a laboratory situation -- after all, if most people spill on their shirt, they don't have a hole there directly to their digestive system. You can ask your PI to buy disposable, waterproof plastic aprons to go over the top of your lab coat.

Sometimes tubes get clogged. To prevent this, you need to flush them often. Flushing also helps keep them from smelling bad, and if you have a button, it keeps formula from solidifying and breaking your anti-reflux valve.

It is very tempting to say "It'll be fine for a few hours" and not flush them, but resist this temptation! It's not worth it. I broke my anti-reflux valve on my latest tube and now it's a rush to connect and disconnect before things overflow too much.

"flushing" a tube: pushing water through them with a syringe





anti-reflux valve: the part of the tube that keeps your stomach contents from flowing back out of you

People say you can unclog tubes by flushing with coca-cola, but I've heard that that can increase risk of later clogs. Talk to your doctor about what to do.

There's a strange thing that happens when I'm hungry; my tube gets kind of sucked deeper into my stomach?
It feels weird, but nothing's wrong with your tube!

For me, I can fix this problem by putting a little bit in my stomach, either by drinking orally or doing feeds, or even just some water.
This solution isn't available to everyone, but it works for me.

If your stoma has been feeling fine for a while and then suddenly starts bleeding and hurting, you may need a tube change.

My gastroenterologist said nothing was wrong, that they just hurt sometimes and I had to just deal with it, and then my tube fell out and had really sharp calcifications all over it, which hurt! The new tube did not hurt at all.

If your tube falls out, it's not life threatening, but it's urgent. Stomas close really fast, within a few hours. If you can't replace it yourself, you need to go to the ER. They can replace it there.

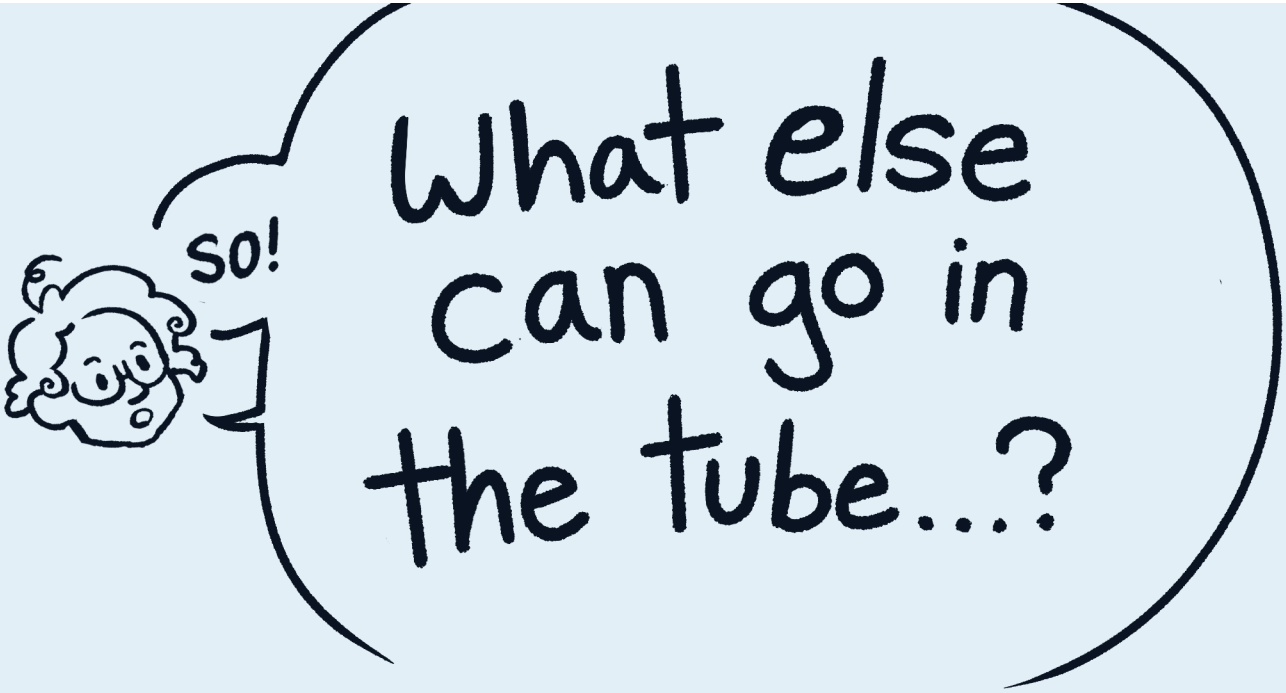
I tape gauze over the stoma to keep it from leaking stomach contents while I wait for it to be replaced.

Please advocate for yourself. You know your body best. If you feel like something is wrong, people should take that seriously.

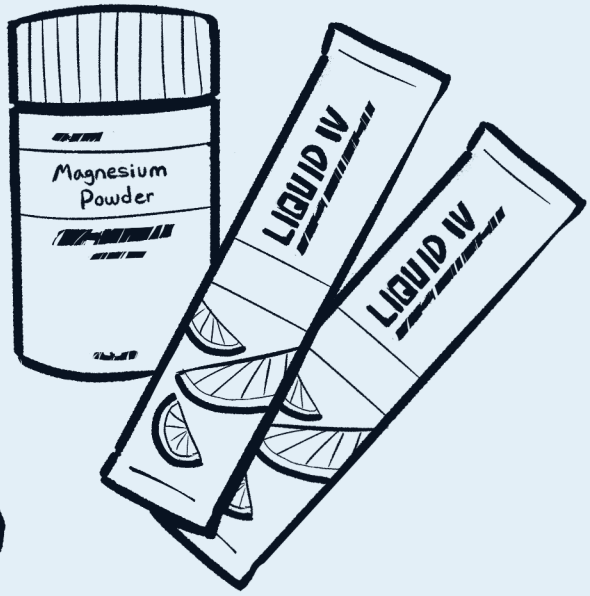
If you feel like something is wrong, it probably is.

I kept waking up in the night to vomit formula and said I wanted to change formulas, and the gastroenterologist insisted that the formula I was using was the best one for me. Eventually, I convinced him to try a different one and I have much less night vomiting. I use Fibersource. I've also heard lots of good things about Kate Farms. It really depends on your personal needs.

If formula doesn't work for you, you can blend your own food or look for food blends premade. I am not experienced with this, but there are many people out there doing feeds this way! You need to blend it very thin and strain it.
Experiment!
kelpforestdwellers recommends looking for Facebook groups, Whole Story Meals, Liquid Hope, and Nestlé (which also makes regular formula.)



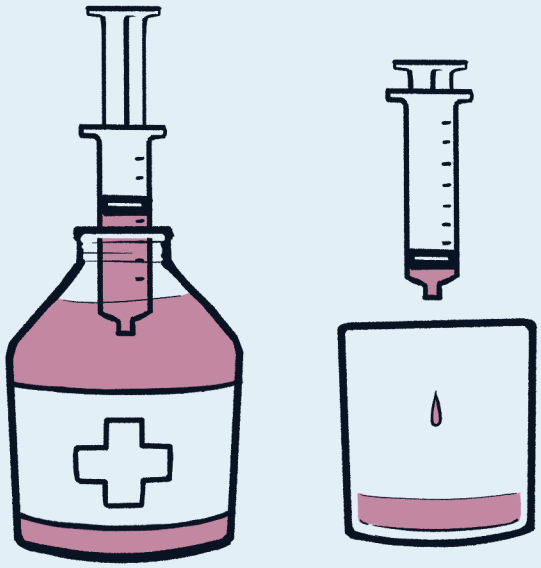
If you have POTS and aren't doing feeds round the clock, you can do fluids through your tube! It keeps me from needing IVs so often. I mix water with liquid IV and powdered magnesium and run my tube, and it really helps (it's easier than remembering to drink one or two sips every few minutes.)



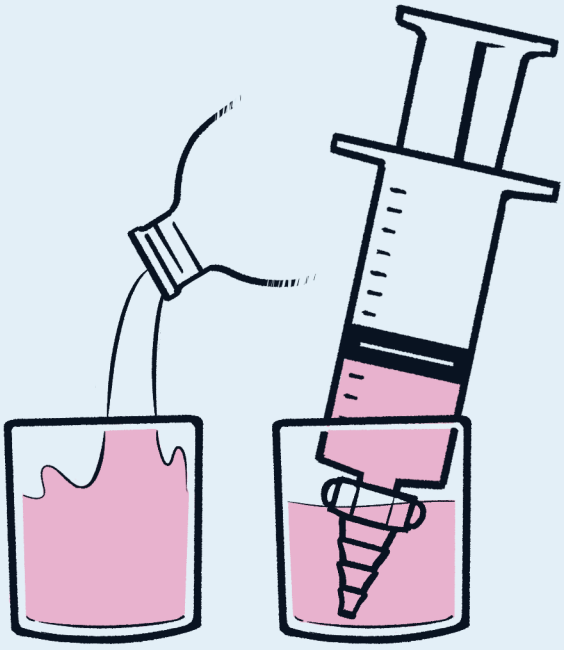
You can do meds through your tube. Try and get as many in liquid form as possible, and the other ones you can use a pill crusher and dissolve in water. However, not all pills can be crushed -- talk to your pharmacist and they'll let you know which ones you can crush and which ones you can't. If you have trouble swallowing pills this can be really helpful!

You can get different size syringes to put meds in your tube. Liquid meds go in best with a syringe closely matched to the amount of liquid you need, but they don't all work with ENFit.

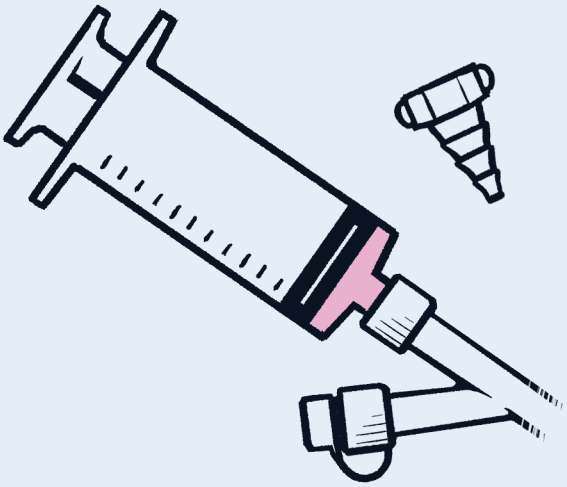
so I measure with a small syringe,
squirt it into a cup,



and push it through my tube with added water and a larger ENFit syringe, using my Christmas tree connector to suck the medicine out of the cup.



Then you unscrew the connector and screw the syringe into your tube or extension set.



The connector allows me to get more of the medicine out than the syringe on its own.

Even if you use ENFit, your feed bags will probably come with unscrewable Christmas tree connectors. Save them for this!

I wish you so much luck and joy with your tube! Mine truly changed my life and I am so grateful for it. It can be hard, and awful, and disgusting, but nutrition is so worth it. It's astonishing how much better you can feel when you're not malnourished.
If you have any other questions, the following page is a list of online resources that may be helpful. You can also contact me on Discord: peromyscus_keeni.

ASPEN (American Society for Parenteral and Enteral Nutrition)
https://www.nutritioncare.org

Feeding Tube Awareness Foundationhttp://www.feedingtubeawareness.org

The Oley Foundation: https://oley.org

The Blend magazine: https://www.theblendmag.com

You can also find people on social media discussing their experiences with feeding tubes! Just like with this zine, remember to be critical of health information you find on the internet -- I'm not endorsing any particular account, but posts like these can be helpful real-world examples and visual reference:

PEG long tube and central line:
https://www.instagram.com/p/BwIPT8OnPsU/

Infinity pump and IV pump:
https://www.instagram.com/reel/CcaWphTMuhY/

Button (probably a G tube?) hooked up
https://www.instagram.com/reel/CuPdhbsLh_y/

What a button looks like outside a person:
https://www.instagram.com/p/CE1k60RgzIl/

Someone with both a G tube and a J tube
https://www.instagram.com/p/B8iJh53ASFI/

Tube taped with griploc and showing a bottle of formula instead of a bag:
https://www.instagram.com/p/CLCBOpODyTa/

Central line and hooked up button:
https://www.instagram.com/p/Be8KoQ3BaD3/

A really great Process Video:
https://www.instagram.com/reel/CuxOJn9gl48/

Showing GJ ports:
https://www.instagram.com/p/BuKZK4unkbx/

Changing a button:
https://www.instagram.com/reel/CWN2EdpgKwt/

Nasal tube, including a back of throat picture:
https://www.instagram.com/p/Bl0c4uIAuw7/

Another nasal tube:
https://www.instagram.com/p/B8e6ksEhvn9/